Indiana State
Cancer Registry
News Briefs

Indiana State Department of Health

NEW METHOD FOR SENDING IN DATA
SAVES TIME AND MONEY

The Indiana State Cancer Registry (ISCR) now has an FTP site where hospitals and other facilities can submit data instead of sending diskettes. FTP stands for "File Transfer Protocol," and it refers to a special kind of Internet site. Most Internet sites have content that you can view in a web browser, but an FTP site is a place where you can download files (that is, copy files from the FTP site to your computer), or upload files (that is, copy files from your computer to the FTP site).

For security reasons, access to the FTP site is restricted to facilities that have installed a special program written specifically to submit data to ISCR through the FTP site. This program will make an encrypted copy of your data (that is, the copy of your data will be scrambled so it can't be read by hackers or other unscrupulous eavesdroppers) and upload it to the FTP site. From there, it can be accessed by ISCR and loaded into the State Registry database.

Before using the FTP site to submit your data, check with your HIPAA Compliance Officer to ensure this method meets your internal policies and safeguards. The following information should be given to your HIPAA Compliance Officer to assist in making this decision: The data is encrypted using the Advanced Encryption Standard (AES), which is approved for government use by the National Institute of Standards and Technology (NIST) in Federal Information Processing Standards Publication 197 (FIPS-197, available at http://csrc.nist.gov/publications/fips/fips197/fips-197.pdf). The encryption key is randomly generated from the user's mouse movements and protected by 2048-bit RSA public key encryption, which is comparable to PGP.

Sometime soon we will be sending you a CD or diskette with this special FTP program along with written instructions on how to install and use it. Although we believe the written instructions are all you'll need to install and use the program, please feel free to call or e-mail if you require any assistance. Contact information will be included in the instructions.

We think you'll find the new FTP program to be very simple to use and far more convenient than using diskettes.

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CERTIFIED TUMOR
REGISTRAR (CTR) EXAM
DEADLINE

July 31, 2004   Application Deadline
September 11, 2004   Testing Begins
September 25, 2004   Testing Ends

Obtain the 2004 CTR Exam Handbook for Candidates and an Exam Application at: http://www.ctrexam.org/exam/handbook.htm1

The Certification Examination will be administered during a 2-week testing period on a daily basis at over 700 computer-based testing facilities worldwide. Testing locations can be found at: http://www.lasergrade.com/ncr.html.

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CONFIDENTIALITY REMINDERS AND HIPAA UPDATES

Please be aware of confidentiality issues when you contact us with questions that refer to specific patients. The best way to communicate is to speak directly with one of our ISCR staff by telephone. If this is not possible, other methods for communicating about specific patients are via fax or e-mail. E-mail correspondence should not contain patient names or other specific identifying information, such as a Social Security Number. Acceptable options to reference specific patients might be to use your hospital's unique Accession Number or the Death Certificate Number.

Before you use any of these methods to communicate electronically about specific patients, consult with your facility's HIPAA Compliance Officer to ensure it meets your internal HIPAA policies. Your facility is responsible for disclosures, so you need to identify the most appropriate method for electronically communicating with ISCR about specific patients. You should also check with your HIPAA Compliance Officer about the method you use for routinely submitting data to ISCR. You may want to ask them whether data sent on diskettes via regular mail need to be encrypted or not. Also check with them about submitting data via the new FTP site, as described in the lead article of this newsletter.

More on HIPAA, from the North American Association of Central Cancer Registries' (NAACCR) Frequently Asked Question (#11 revised answer from 3/31/03) at http://www.naaccr.org/index.asp?Col_SectionKey=10&Col_ContentID=101:

11. Will private practice physicians and hospitals be permitted to continue to provide follow-up and treatment information to hospital cancer registries without patient authorization?

Yes. Although private practice physicians and hospitals are health providers, and thus covered under the provisions of the HIPAA privacy regulations, they may continue to provide cancer patient follow-up and treatment information to hospital cancer registries without patient authorization when both the physician and the hospital has or had a relationship with the patient.

Under the HIPAA Final Privacy Rule, private practice physicians and hospitals may disclose confidential patient information to hospitals for the purpose of treatment, payment and **health care operations** (emphasis added) (quality assessment/improvement is considered a health care operation). A business associate agreement is not required between a hospital and physician for such purposes (emphasis added).

Section 164.506(c)(4), states, in relevant part, that
A Covered Entity may disclose protected health information to another covered entity for health care operations activities of the entity that receives the information, if each entity either has or had a relationship with the individual who is the subject of the protected health information being requested, the protected health information pertains to such relationship, and the disclosure is:
(i) For a purpose listed in paragraph (1) or (2) of the definition of health care operations Section 164.501 of the Privacy Rule defines health care operations and Paragraph (1) of the definition provides, in relevant part:

(1) Conducting quality assessment and improvement activities, including outcomes evaluation and development of clinical guidelines, **population-based activities related to improving health** (emphasis added) or reducing health care costs, protocol development, case management and case coordination, contacting of health care providers and patients with information about treatment alternatives; and related functions that do not include treatment.
Paragraph (2) of the definition provides, in relevant part:
(2) Reviewing the competence or qualifications of health care professionals, evaluating practitioner and provider performance, health plan performance, conducting training programs in which students, trainees, or practitioners in areas of health care learn under supervision to practice or improve their skills as health care providers, training of non- health care professionals, accreditation, certification, licensing, or credentialing activities.

Thus, as hospital cancer registries collect treatment and follow-up data in compliance with state law and for the purpose of "population-based activities related to improving health" this is a permitted disclosure without requirement of patient authorization. It may also be noted that many hospital cancer registries collect this information for "conducting quality assessment and improvement activities", for "reviewing the competence or qualifications of health care professionals", for "conducting training programs" and for "accreditation, certification, licensing, or credentialing activities". All of these are specifically permitted in paragraphs (1) and (2) shown above.

Note that Section 164.506(c)(4) specifically provides for the ability of one covered entity to provide an individual's PHI to another covered entity, if the receiving covered entity "has or had" a relationship with the individual. This specific reference to the past tense is important since it means that a covered entity's ability to obtain information about a patient need not be "cut-off" if the patient no longer has a direct relationship with the covered entity.

CONFIDENTIALITY REMINDERS AND HIPAA UPDATES *(Continued from page 2)*

While exchange of treatment and follow-up information is permitted without patient authorization under the provisions described above, an accounting of disclosure must still be maintained.
1 45 CFR 160.103

12. What if a patient does not want follow–up information to be collected?
State-mandated cancer reporting typically does not require patient informed consent nor can individuals elect to be removed from reporting. In a state which allows the collection of follow–up cancer data for public health purposes, it can be collected regardless of consent from a patient.

Read more about HIPAA from NAACCR at http://www.naaccr.org/index.asp?Col_SectionKey=10&Col_ContentID=101.

REFERENCES

SEER Summary Staging Manual 2000 is available free from SEER by calling 1-800-4-CANCER (1-800-422-6237) or ordering online at: http://seer.cancer.gov/cgi-bin/pubs/order1.pl.

The references below can be found online, or contact the State Registry if you need a hard copy.

Corrections/Clarifications to AJCC 6th Ed., released 7-21-03: http://www.cancerstaging.org/clarifications.html

Oncology Drugs References - to help you classify drugs as chemotherapy, immunotherapy, hormone, etc. when abstracting a case: SEER Book 8 - Antineoplastic Drugs. Order a free copy at:
http://seer.cancer.gov/cgi-bin/pubs/order1.pl?BOOK,CODING,MONO.

A list of additional oncology agents not listed in SEER Book 8 can be found at:
http://seer.cancer.gov/tools/SEER.Book8.Addenda.pdf.

CONFIRM NUMBER OF CASES SENT TO STATE REGISTRY

When you receive the confirmation form from the State Registry to let you know your cases were received and loaded, look at the number of cases that were submitted to ensure it agrees with your records. If you think you submitted more records than the confirmation form shows, let us know so we can resolve any discrepancies.

TRAINING & EDUCATIONAL OPPORTUNITIES

Online FREE Training from SEER
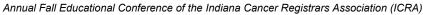   http://www.training.seer.cancer.gov

Online FREE Brain Tumor Registry Reporting Training Materials from CDC
   http://www.cdc.gov/cancer/npcr/training/index.htm

Principles of Oncology for Cancer Registry Professionals (Potomac, MD)
   October 4 - 8, 2004
   December 6 - 10, 2004
   http://seer.cancer.gov/training/oncology
   Contact the Indiana State Cancer Registry if you wish to apply for financial assistance to attend this course.

Annual Fall Educational Conference of the Indiana Cancer Registrars Association (ICRA)
   SAVE THE DATES: Thursday and Friday, November 4-5, 2004 in Indianapolis, IN (at the Marten House)
   Further information will be distributed later, or contact either of the two Program Co-Chairs for questions now:
   Martha Hill   (812) 353-9295 or mhill@bloomhealth.org
   Karen McCracken   (317) 274-8793 or kmccrack@clarian.org

TEXT DOCUMENTATION REMINDERS

Text documentation of medical record information that supports/explains the codes selected for data items is critical for the processes performed at the state cancer registry. Examples of the text fields available and information to be recorded are listed below.

History **and** **Physical** (RMCDS field: "DX Proc PE")

Include date of H & P and demographic information, such as age, race, ethnicity, and sex when documenting text from the physical exam. Also describe pertinent history, clinical findings, and impression pertaining to cancer diagnosis.

> *Example of required demographic documentation*: Enter "H&P: 5/11/03 - 57 YO W NON-HISP M" to describe a 57 year-old, white, non-Hispanic male. (Then describe history and findings.)

Description **of** **Diagnosis** (RMCDS fields: "Primary Site Title, Histology Title, Dx Proc Path")

Describe the specific primary site, laterality, histology, behavior, and grade.

> *Example*: BREAST, RT UPPER OUTER QUAD (OR UOQ). WELL-DIFF, INVASIVE DUCTAL CARCINOMA

Staging

Describe the extent of disease: lymph node involvement or non-involvement; nearby organs that were or were not involved; presence or absence of distant metastasis, etc.

> Example: P. DIFF. ADENOCA. SIGMOID COLON, INVADES THRU. THE MUSCULARIS PROPRIA. LN NEG.

Tumor **Size** (May be recorded in "Description of Diagnosis" or specific field for "Size.")

Describe measurements and specify mm, cm, depth of invasion.

> *Example*: 0.75 MM DEPTH or 2.3 X 4.1 X 5.0 CM

Treatment - 4 W's (Document for biopsies, diagnostic endoscopy, surgery, and all other treatment modalities.)

When was treatment performed or begun?
What specific type of treatment was performed or given? (description of surgery, RT, chemo, etc.)
Where was treatment done? (name of facility or physician's name; city & state if not in Indiana)
Why wasn't treatment done? (if applicable)

> *Examples*: 4/21/03 Left mod. rad. mastectomy at (name of hosp.) w/ 3/10 LN pos. 5/11/04 Beam radiation started at (name of radiation facility). Patient did not want to take Tamoxifen.

Would you like to get your next newsletter via e-mail? If so, send your e-mail address to lwitheri@isdh.state.in.us and you will receive an electronic format of the newsletter next month.

DEATH CERTIFICATE LETTERS

Death clearance is defined as matching death (mortality) files against registry (incidence) files to identify potential missed reports for cancer incidence. The goal is to achieve the lowest possible number of cancer deaths that do not match an incident case so that there are a reduced number of Death Certificate Only (DCO) cases. Approximately 2,500 cancer diagnoses that have never been reported are identified each year on Death Certificates.

Importance of responding to death certificate letters by providing more complete information on a timely basis:
- Improves completeness and accuracy of data
- May identify reporting sources that are not reporting, as required
- May identify areas within a hospital that are being overlooked during casefinding activities
- May identify specific cancers that are being underreported
- Provides more accurate statistics
- Allows better assessment of cancer burden in Indiana
- Allows Indiana to maintain NAACCR Gold Certification by having < 3% Death Certificate Only (DCO) cases
- Allows Indiana data to be published in *U.S. Cancer Statistics* & *Cancer Incidence in North America*
- Complies with CDC/NPCR grant requirements so that funding can continue

Even if your reference date is later than 1987, you are required, by law, to report all cases diagnosed since 1987, which is the State's reference date. Therefore, if you receive a death certificate letter about a patient who was diagnosed at your hospital before your reference date but in 1987 or later, you must report the case.

State reporting requirements are different from the case eligibility rules for ACoS hospitals. Some cases are not required by ACoS standards, but ARE reportable to the State because of the law. For example, patients seen only in consultation and pathology-only cases are reportable to the State. Class of Case 3 or 4 cases for your hospital must be reported to the State if diagnosed after 1986. (These "State-reportable" cases can be reported with your regular electronic submissions, by sending in hard copies of medical records, or by completing a paper abstract or the form that was sent with the death certificate letter.)

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BACKING UP YOUR DATA

Remember to make a backup copy of your data for your own hospital's security purposes, either daily, weekly, or however often you enter cases. Even if your computer is on the hospital's network, you should not assume they are making a backup copy every night. Verify this with them and test it by trying to restore one of their backup copies to be sure it works. If you do not have a backup copy of your data and your computer crashes or is damaged through water, fire, theft, weather, etc., all data you have entered since your last submission to the State will be lost. This type of security backup of all cases may be different than the routine backup of newly entered cases you send to the State, depending on what software program you are using. If you do not know how to make a security backup, contact your Information Technology Service for assistance. If they have questions, they can contact Steve Nygaard at ISCR: snygaard@isdh.state.in.us or (317) 233-7099.

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